

University of Dundee

The Brittle Bone Society

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Publication date:
2018

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Citation for published version (APA):
Nabizadeh, G. (Ed.), Vaughan, P. (Ed.), Murray, C., Balson, E., Laird, C., & Herd, D. (Ed.) (2018). *The Brittle Bone Society: Celebrating 50 Years*. UniVerse.

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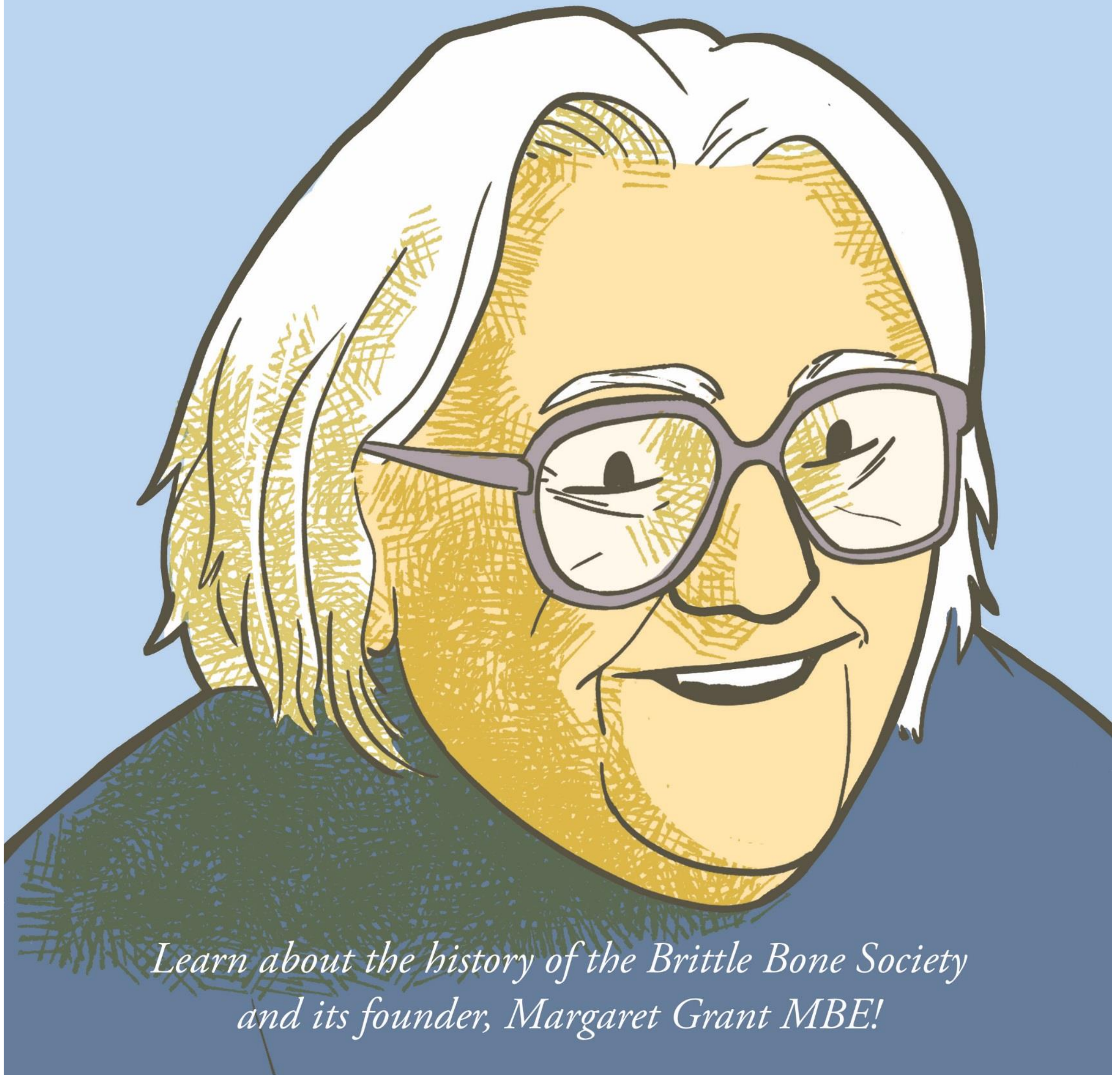
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THE BRITTLE BONE SOCIETY

Celebrating 50 Years



*Learn about the history of the Brittle Bone Society
and its founder, Margaret Grant MBE!*

WELCOME TO THE BRITTLE BONE SOCIETY 50TH ANNIVERSARY COMIC!

The mission of the Brittle Bone Society is to improve the quality of life of people diagnosed with Osteogenesis Imperfecta and their families. We have raised millions of pounds over the years, provide funds for wheelchairs and equipment, hold events for families, and act as advocates for people with OI. We are also committed to raising awareness of Brittle Bone disease, and through our Medical Advisory Board and research grants programme, to advancing knowledge about the condition.

We are very happy to have worked with Dundee Comics Creative Space (DCCS) to produce this souvenir comic celebrating the history of the Society, with a focus on our founder, Margaret Grant MBE, and the experiences of members.



We hope you enjoy this comic,
Elaine Healey (Chairperson) & Patricia Osborne (CEO) Brittle Bone Society.

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Edited by Golnar Nabizadeh, Phillip Vaughan and Chris Murray. Written by Chris Murray.
Artwork by Elliot Balson. Colours by Catriona Laird. Production by Damon Herd.

With thanks to Patricia Osborne, Coreen Kelday, and staff and volunteers at The Brittle Bone Society plus The Board of Trustees at The BBS.

Brittle Bone Society charity registration no. England and Wales 272100 and Scotland SCO10951



Brittle Bone Society 50th Anniversary comic published by UniVerse, the University of Dundee, Perth Road, Dundee, Scotland, UK, DD1 4HT, for The Brittle Bone Society, with production by INK POT Studio. All Rights Reserved. The narratives presented here are drawn from materials provided by the Brittle Bone Society and their members, and represent a fictionalised account of their history and the experiences of individual members. These stories have been approved by the Society.

INK POT and Dundee Comics Creative Space are funded by The Rank Foundation.

OSTEOGENESIS IMPERFECTA, widely known as brittle bone disease, is a group of genetic disorders which result in multiple symptoms.

THE CONDITION AFFECTS AROUND 1 IN EVERY 15,000 PEOPLE. THE MOST COMMON SYMPTOM IS THAT BONES BREAK VERY EASILY.

EVIDENCE OF BRITTLE BONES HAS BEEN FOUND IN EGYPTIAN MUMMIES FROM AROUND 1000 B.C.

THE TERM "OSTEOGENESIS IMPERFECTA" WAS COINED IN 1849 BY WILLEM VROELICK.

DESPITE THIS, UNTIL RECENTLY MEDICAL PROFESSIONALS KNEW LITTLE OR NOTHING ABOUT THE CONDITION.

SO, WHEN MARGARET GRANT WAS BORN WITH OI IN 1933 THERE WAS LITTLE SUPPORT OR UNDERSTANDING FROM DOCTORS, AND THIS CONTINUED THROUGHOUT HER YOUTH.

LET ME KNOW IF THIS HURTS, MARGARET.

UP TO THE AGE OF 13 MARGARET WAS IN AND OUT OF HOSPITAL. DURING THE WAR SHE WAS AT STRACATHRO HOSPITAL WHERE SHE ASSISTED THE NURSE BY ROLLING UP BANDAGES AND LIT CIGARETTES FOR WOUNDED SOLDIERS.

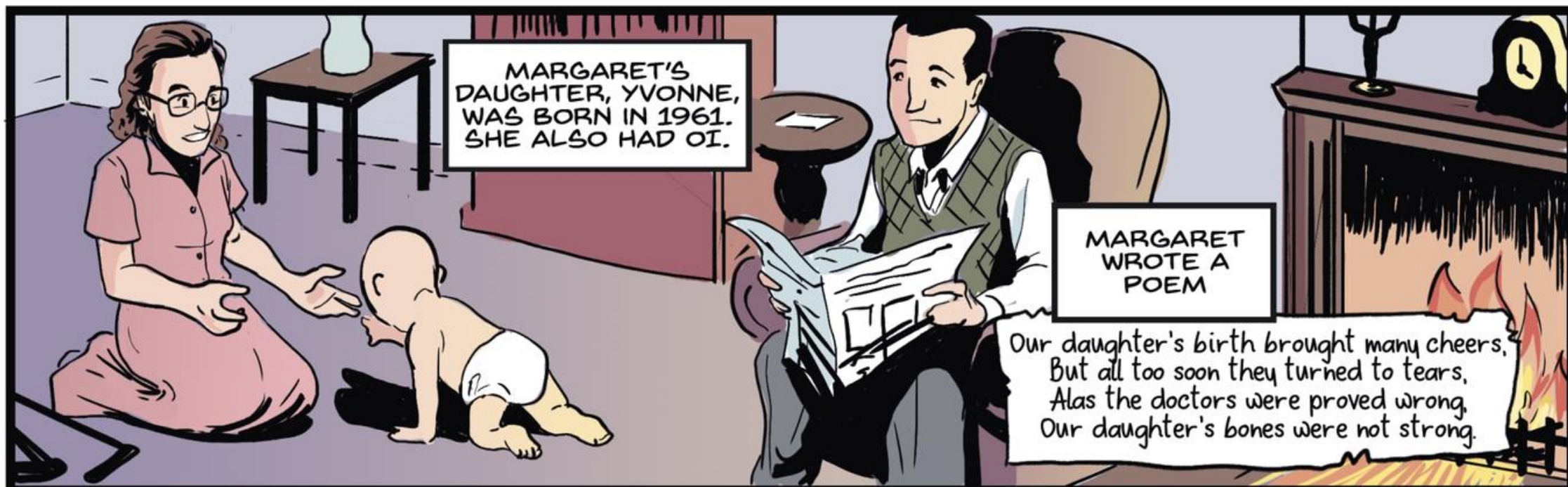


HER PARENTS COULD ONLY VISIT AT WEEKENDS. THERE WAS NO TREATMENT AS SUCH. THE ONLY MEDICAL ADVICE WAS TO DRINK MILK.

AT 14 MARGARET STARTED AT TREFOIL SCHOOL IN EDINBURGH, WHICH CATERED FOR CHILDREN WITH SPECIAL NEEDS. UP TO THAT POINT HER FATHER TAUGHT HER.



MARGARET'S DAUGHTER, YVONNE, WAS BORN IN 1961. SHE ALSO HAD OI.



MARGARET WROTE A POEM

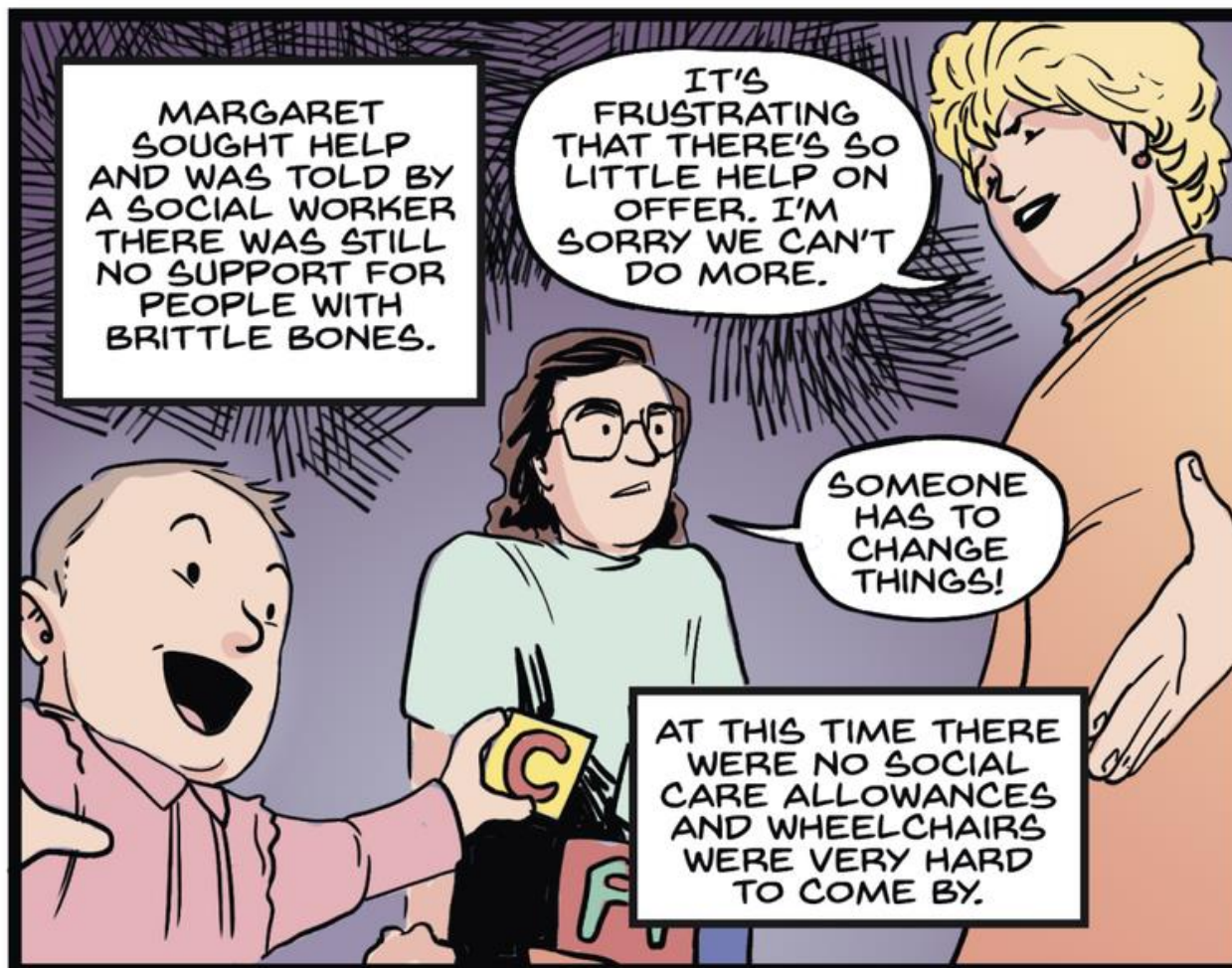
Our daughter's birth brought many cheers,
But all too soon they turned to tears,
Alas the doctors were proved wrong,
Our daughter's bones were not strong.

MARGARET SOUGHT HELP AND WAS TOLD BY A SOCIAL WORKER THERE WAS STILL NO SUPPORT FOR PEOPLE WITH BRITTLE BONES.

IT'S FRUSTRATING THAT THERE'S SO LITTLE HELP ON OFFER. I'M SORRY WE CAN'T DO MORE.

SOMEONE HAS TO CHANGE THINGS!

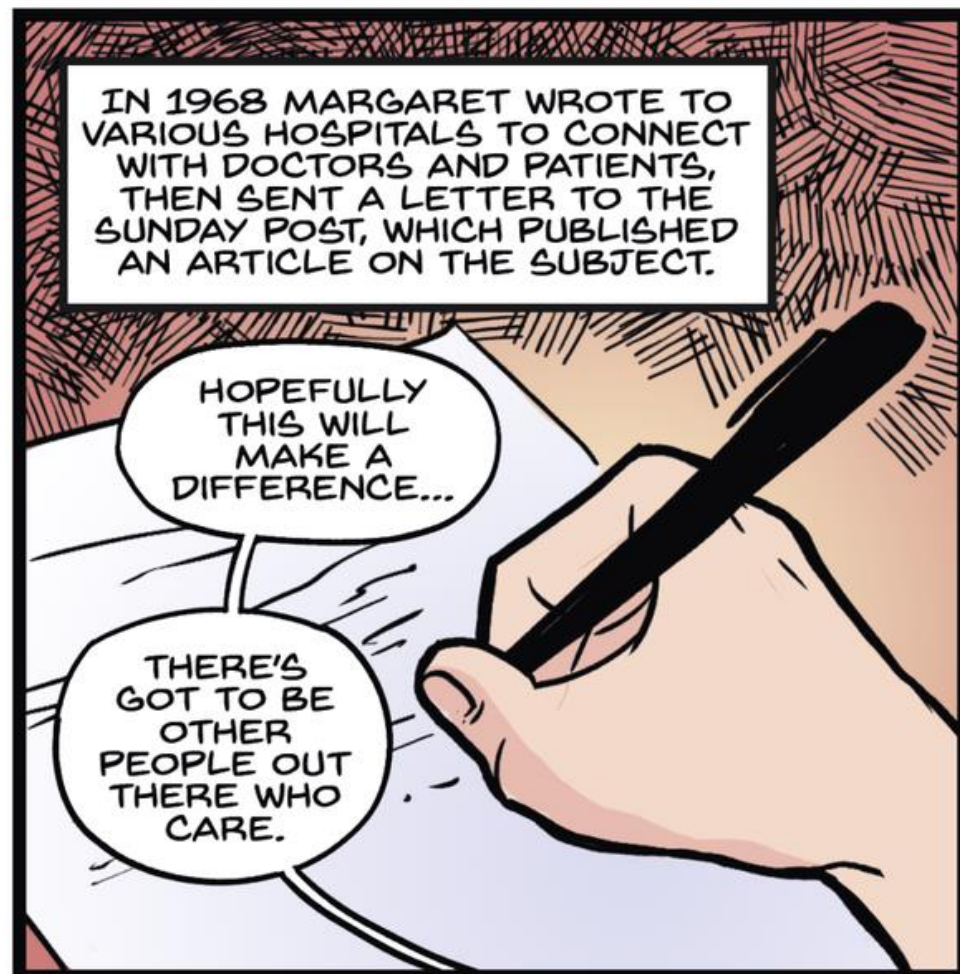
AT THIS TIME THERE WERE NO SOCIAL CARE ALLOWANCES AND WHEELCHAIRS WERE VERY HARD TO COME BY.



IN 1968 MARGARET WROTE TO VARIOUS HOSPITALS TO CONNECT WITH DOCTORS AND PATIENTS, THEN SENT A LETTER TO THE SUNDAY POST, WHICH PUBLISHED AN ARTICLE ON THE SUBJECT.

HOPEFULLY THIS WILL MAKE A DIFFERENCE...

THERE'S GOT TO BE OTHER PEOPLE OUT THERE WHO CARE.



IT DID. LATER THAT YEAR MARGARET ESTABLISHED THE BRITTLE BONE SOCIETY IN DUNDEE.

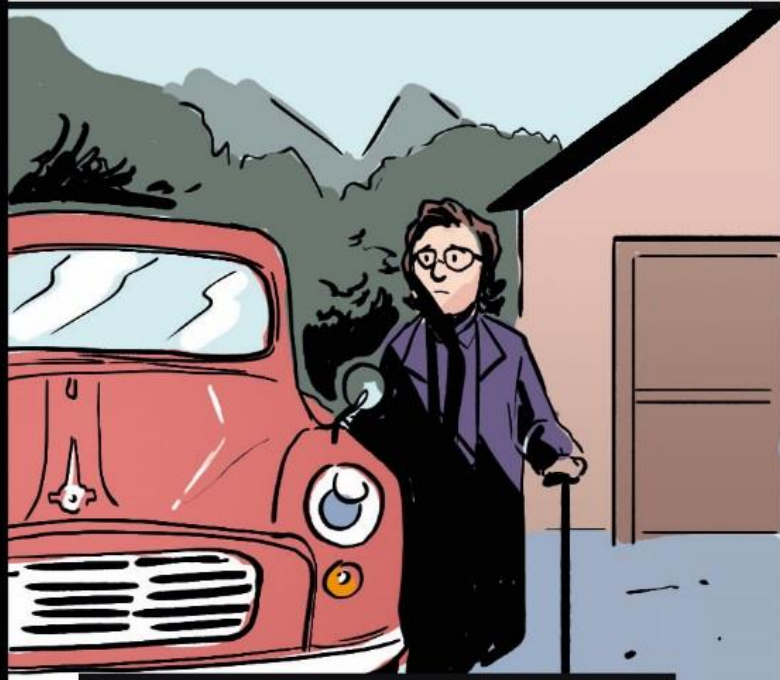
IT WAS THE WORLD'S FIRST CHARITY FOR PEOPLE WITH OSTEOGENESIS IMPERFECTA.



DESPITE THIS SUCCESS, TIMES WERE TOUGH. THE FAMILY SOLD FURNITURE TO PAY THE BILLS. YVONNE WAS AT SCHOOL IN EDINBURGH AND OFTEN ADMITTED TO HOSPITAL THERE, HOWEVER HER PARENTS HAD NO MEANS OF GETTING THROUGH TO SEE HER.

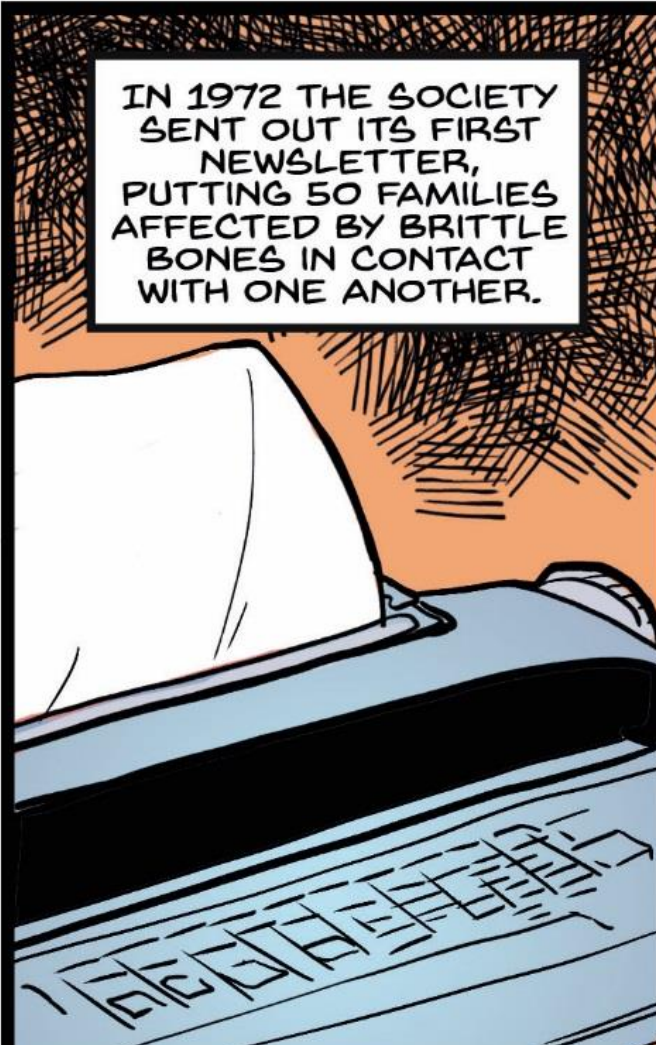


THE SCOTTISH HOME AND HELP DEPARTMENT OFFERED SUPPORT TO FAMILIES DURING THIS PERIOD. IT WAS THE FIRST TIME GOVERNMENT HELP HAD BEEN PROVIDED. MARGARET WAS ENTITLED TO A CAR AND WAS GIVEN A MORRIS MINOR, BUT ONLY BECAUSE TWO DISABLED PEOPLE WERE LIVING IN THE HOUSE.



THE STRICT CRITERIA REQUIRED HER TO LEARN TO DRIVE, AND KEEP THE CAR IN A GARAGE, BUT THEY DIDN'T HAVE ONE AND HAD TO BORROW MONEY TO BUY A GARAGE.

IN 1972 THE SOCIETY SENT OUT ITS FIRST NEWSLETTER, PUTTING 50 FAMILIES AFFECTED BY BRITTLE BONES IN CONTACT WITH ONE ANOTHER.



IN MAY 1973, IBM DONATED AN ELECTRIC TYPEWRITER TO THE SOCIETY, WHICH MADE A CONSIDERABLE DIFFERENCE. A SUPPORT NETWORK WAS NOW IN PLACE, ALLOWING THESE FAMILIES TO SHARE EXPERIENCES.



THE FAMILIES SENT LETTERS, POEMS, AND STORIES TO MARGARET WHO PUBLISHED THEM IN THE NEWSLETTER. THEY NO LONGER FELT ALONE AND ABANDONED.

THE FOLLOWING YEAR THE NATIONAL COMMITTEE WAS FORMED AND THE GROUP OFFICIALLY BECAME A SOCIETY.

THINGS ARE REALLY MOVING NOW.

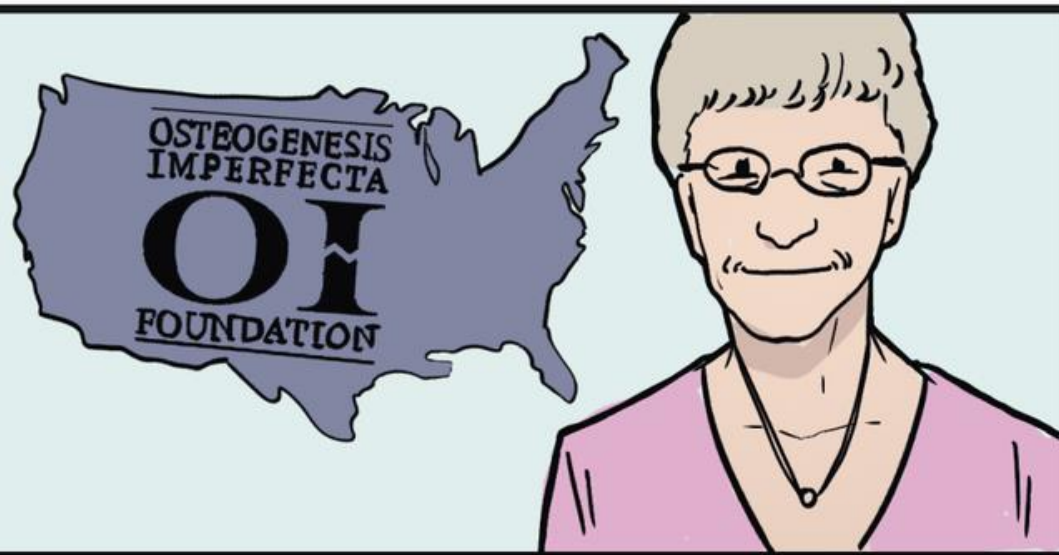


THE FIRST DRAFT CONSTITUTION WAS PRODUCED, AND THE LONGRIDGE BRANCH WAS FORMED, BECOMING THE FIRST OF MANY BRANCHES. THE SOCIETY WAS ALSO ABLE TO LAUNCH A CAMPAIGN THAT SOUGHT TO PROVIDE WHEELCHAIRS FOR CHILDREN AND OTHER MEMBERS.

BY 1974 THE SOCIETY WAS MAKING GREAT PROGRESS. THE FIRST RESEARCH GRANT TO LOOK AT THE CONDITION WAS AWARDED TO DR ROGER SMITH AND DR MARTIN FRANCIS OF THE NUFFIELD ORTHOPAEDIC CENTRE, AND THE FIRST MEDICAL ARTICLE ON THE CONDITION APPEARED IN NOVEMBER 1974 IN THE MIDWIVES' CHRONICLE. IT EXPLAINED THE CAUSE, VARIETIES, INCIDENCE, CLINICAL FEATURES, AND MANAGEMENT OF OI.



MARGARET HAD BY NOW REACHED OUT TO OTHERS IN NUMEROUS COUNTRIES, AND HER EXTENSIVE NETWORK AND EXPERIENCE ALLOWED HER TO COLLABORATE WITH FRIENDS IN THE USA, SUCH AS GEMMA GEISMAN, WHO SET UP THE SISTER ORGANISATION, THE OI FOUNDATION (OIF).



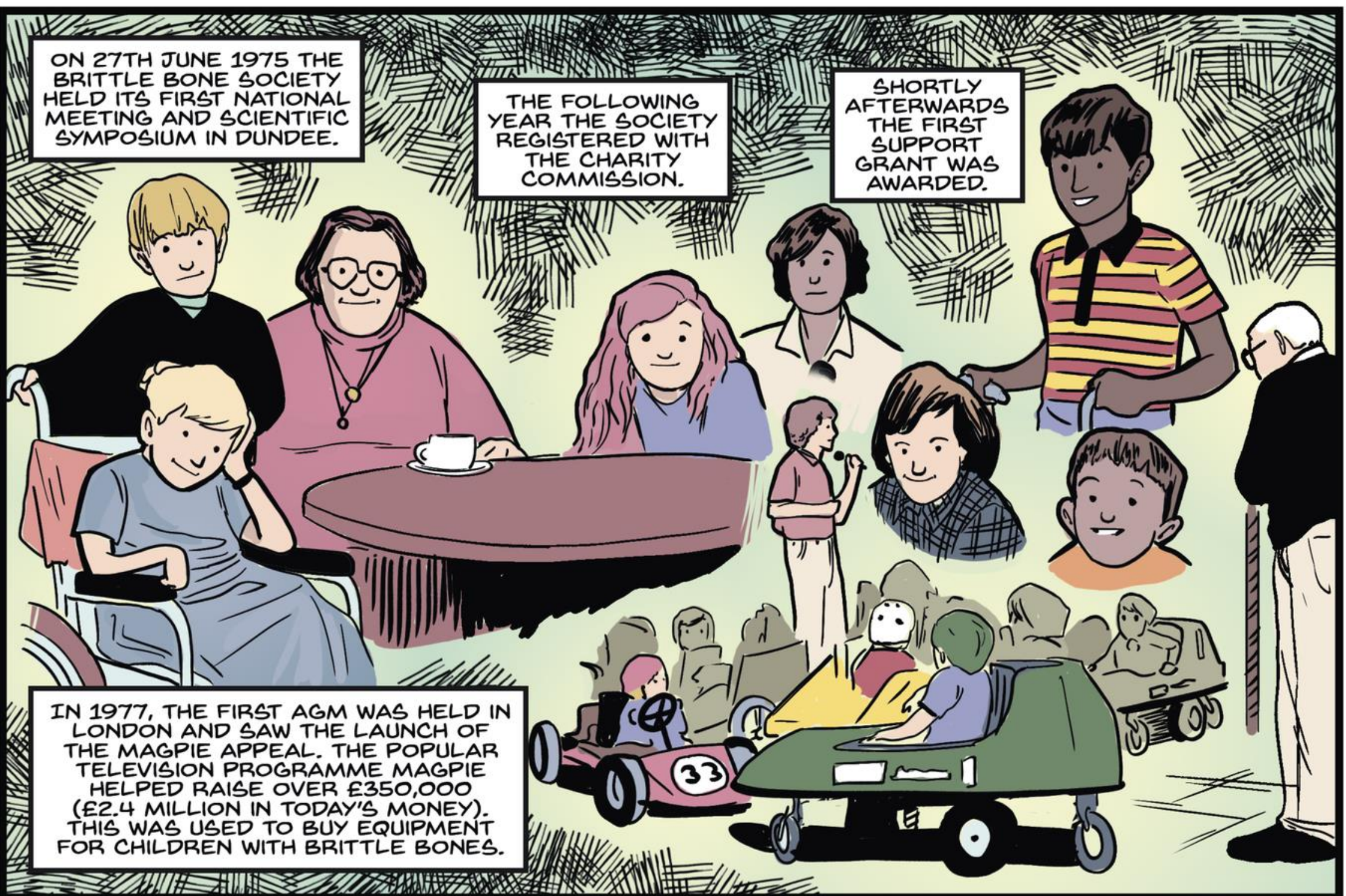
MARGARET WAS ALSO INSTRUMENTAL IN SUPPORTING THE SETUP OF THE EUROPEAN COLLECTIVE OF PATIENT ORGANISATIONS IN EUROPE -- THE OSTEOGENESIS IMPERFECTA FEDERATION EUROPE (OIFE).



ON 27TH JUNE 1975 THE BRITTLE BONE SOCIETY HELD ITS FIRST NATIONAL MEETING AND SCIENTIFIC SYMPOSIUM IN DUNDEE.

THE FOLLOWING YEAR THE SOCIETY REGISTERED WITH THE CHARITY COMMISSION.

SHORTLY AFTERWARDS THE FIRST SUPPORT GRANT WAS AWARDED.

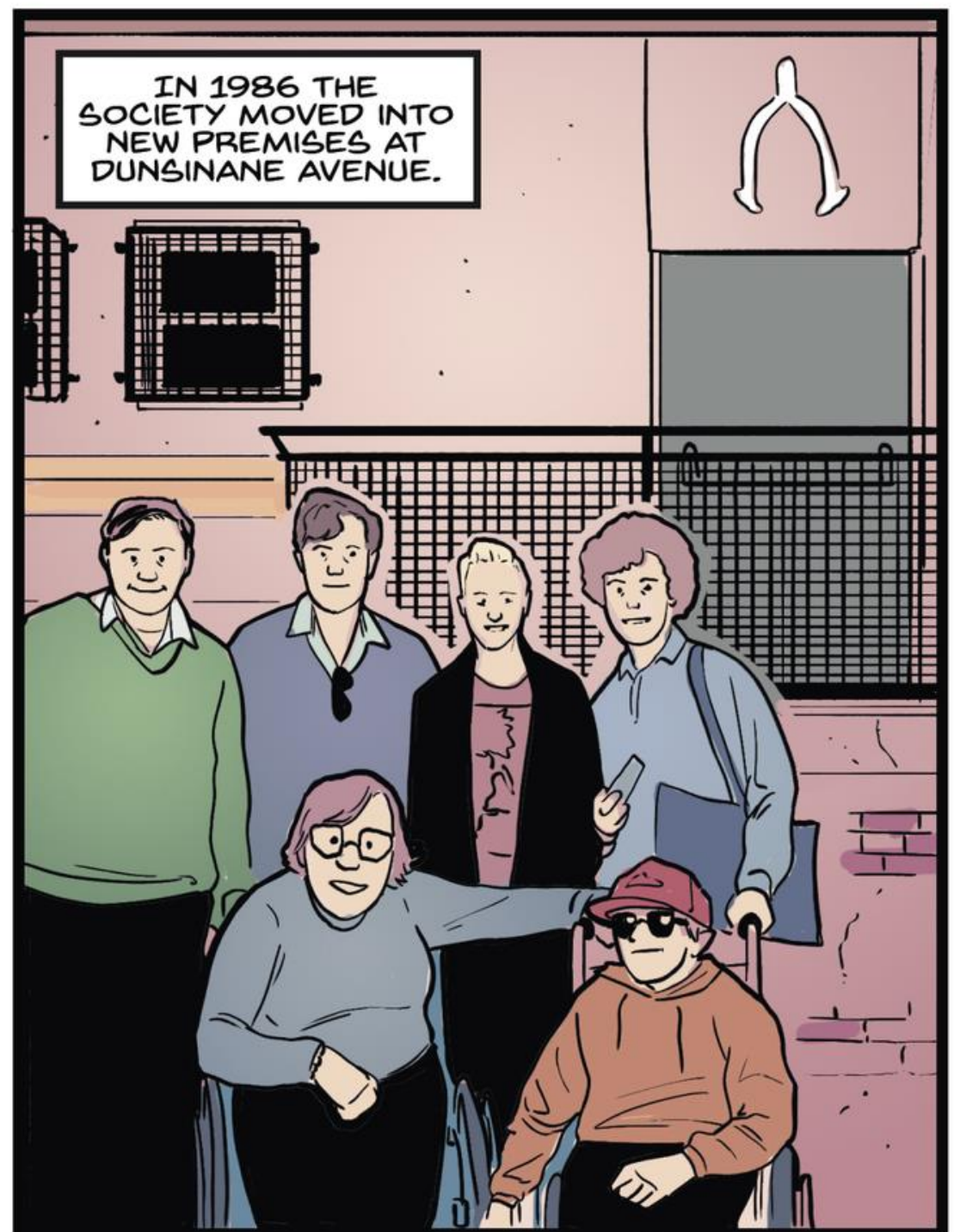
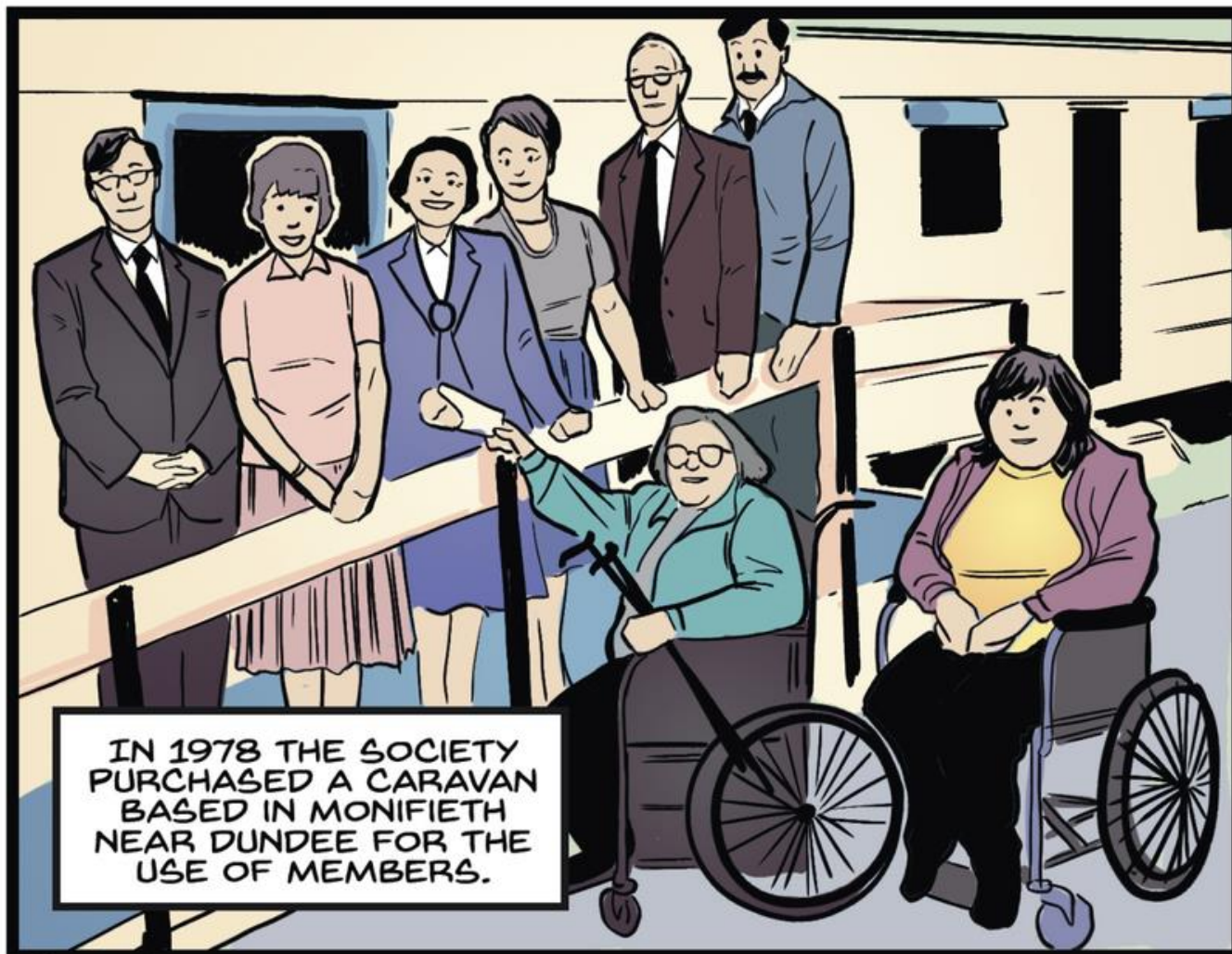


IN 1977, THE FIRST AGM WAS HELD IN LONDON AND SAW THE LAUNCH OF THE MAGPIE APPEAL. THE POPULAR TELEVISION PROGRAMME MAGPIE HELPED RAISE OVER £350,000 (£2.4 MILLION IN TODAY'S MONEY). THIS WAS USED TO BUY EQUIPMENT FOR CHILDREN WITH BRITTLE BONES.

Little Linda's help

FUNDRAISING HAS ALWAYS BEEN AN IMPORTANT PART OF THE SOCIETY'S ACTIVITIES. FUNDERS SUCH AS JOHN AND GERTIE FARMERIE HAVE RAISED THOUSANDS OF POUNDS OVER THE YEARS.

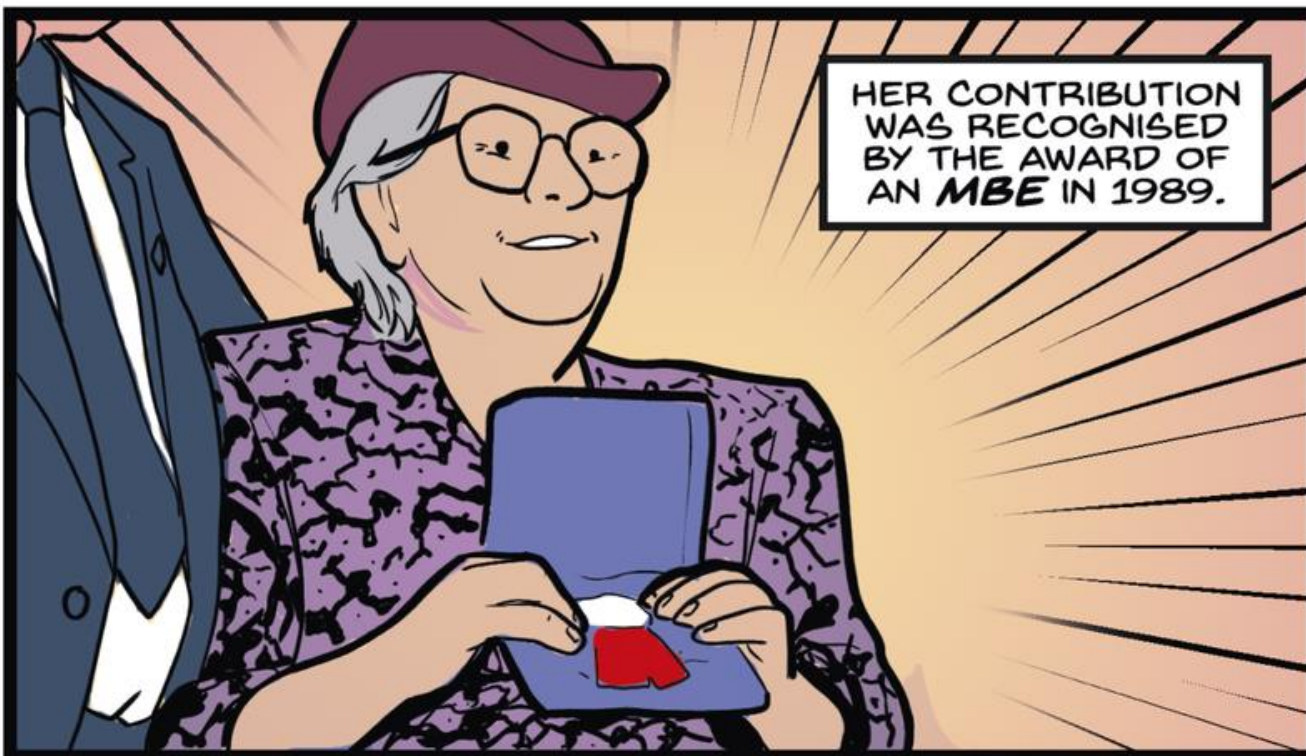




FOR TWENTY YEARS MARGARET GRANT HAD BEEN THE DRIVING FORCE OF SOCIETY AND ITS CHARITABLE WORK.



HER CONTRIBUTION WAS RECOGNISED BY THE AWARD OF AN **MBE** IN 1989.



IN THE EARLY 1990S THE SOCIETY MOVED TO STRATHMARTINE ROAD, AND IN THE MID-90S PURCHASED PREMISES ON GUTHRIE STREET.



IN THE MIDST OF THIS THE YOUTH COMMITTEE WAS ESTABLISHED, PARTLY BECAUSE MANY MEMBERS OF THE SOCIETY HAD EXPERIENCED DIFFICULTIES IN SCHOOL AND THE SOCIETY WANTED TO RECOGNISE AND TACKLE THESE ISSUES.

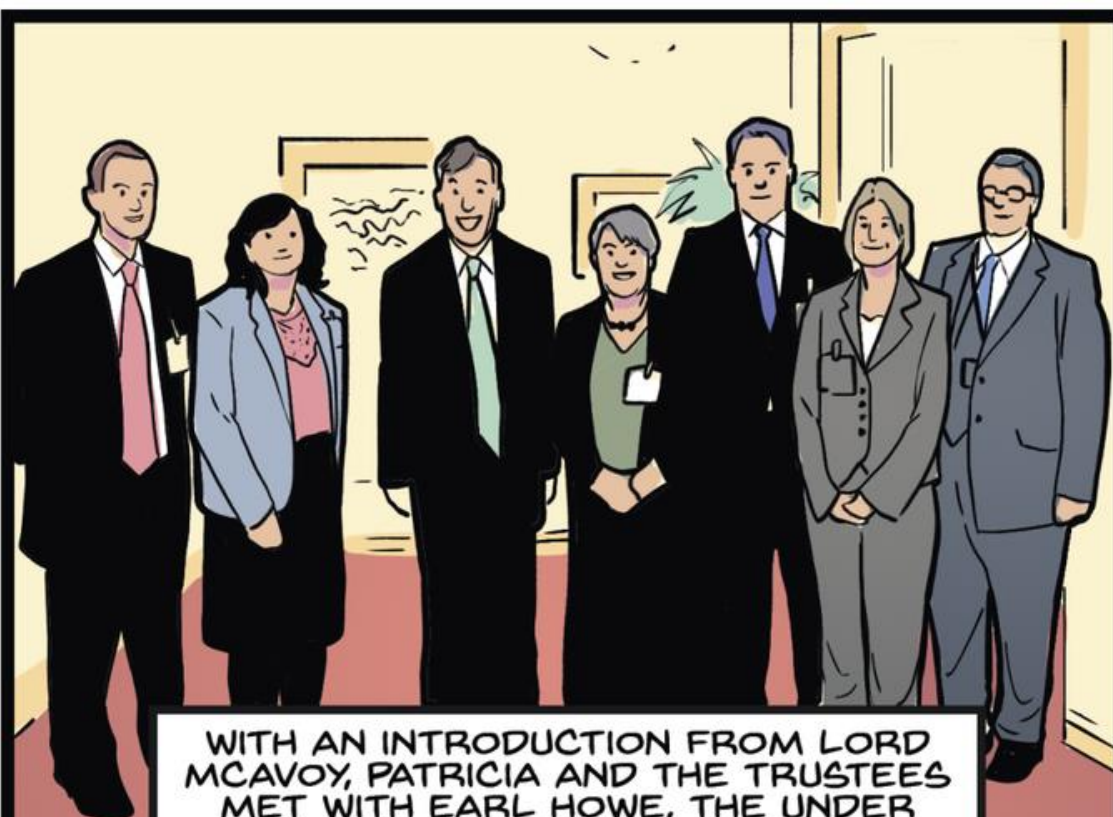
THE SOCIETY LAUNCHED ITS FIRST WEBSITE IN 1997.



PATRICIA OSBORNE WAS APPOINTED AS CEO IN 2009 AND EMBARKED ON A RADICAL MODERNISATION AND UPDATE OF THE SOCIETY.



USING CONTACTS FROM PREVIOUS ROLES FROM HER TIME WORKING IN THE MEDIA AND POLITICS, PATRICIA SET ABOUT ORGANISING THE APPOINTMENT OF THE SOCIETY'S OWN MEDICAL ADVISORY BOARD, AS REQUESTED BY THE TRUSTEE BOARD. THIS TOOK AROUND THREE YEARS OF HARD WORK AND INVOLVED BUILDING RELATIONS WITH NHS CENTRES OF EXCELLENCE.

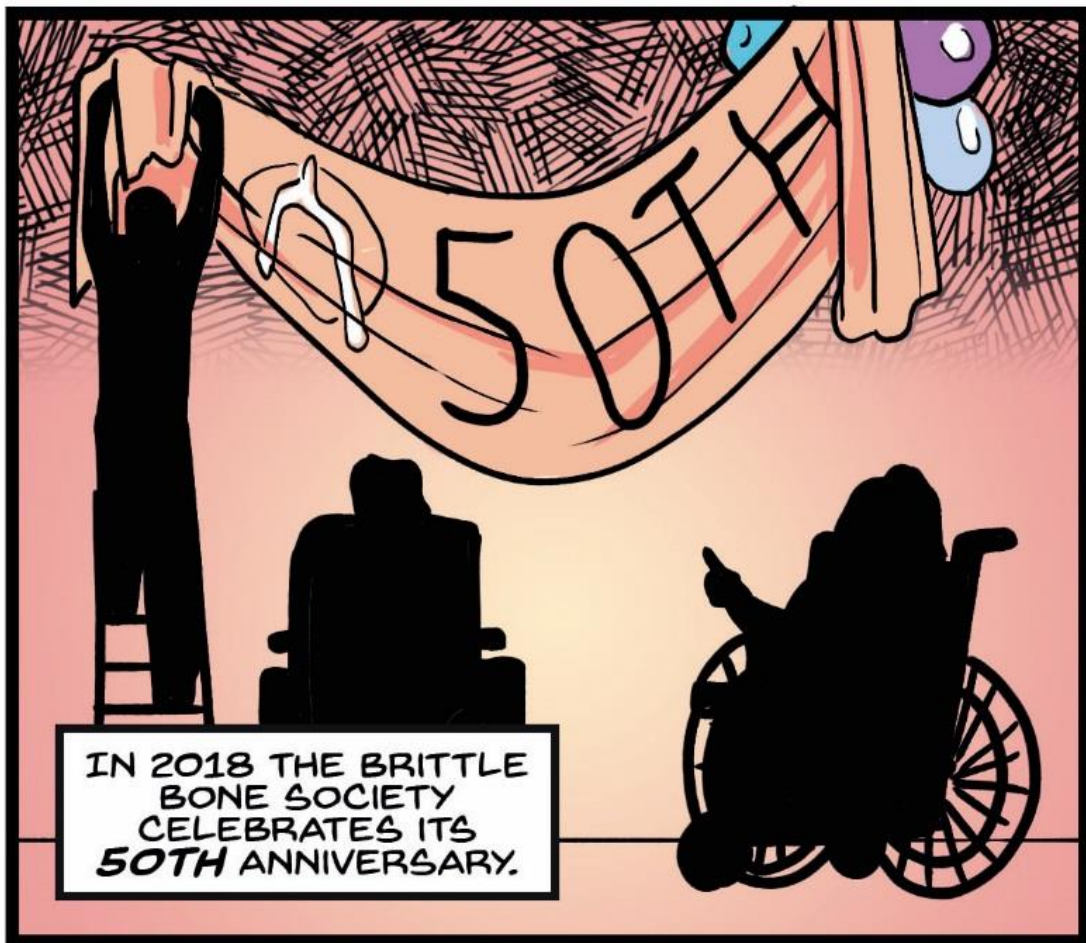


WITH AN INTRODUCTION FROM LORD MCAVOY, PATRICIA AND THE TRUSTEES MET WITH EARL HOWE, THE UNDER PARLIAMENTARY SECRETARY OF STATE FOR HEALTH IN THE HOUSE OF LORDS. THIS ALLOWED SCOPE TO DEVELOP A STRATEGY TO IMPROVE LINKS WITH HEALTHCARE PROFESSIONALS AND WORK TOWARDS THE FORMATION OF A MEDICAL ADVISORY BOARD.

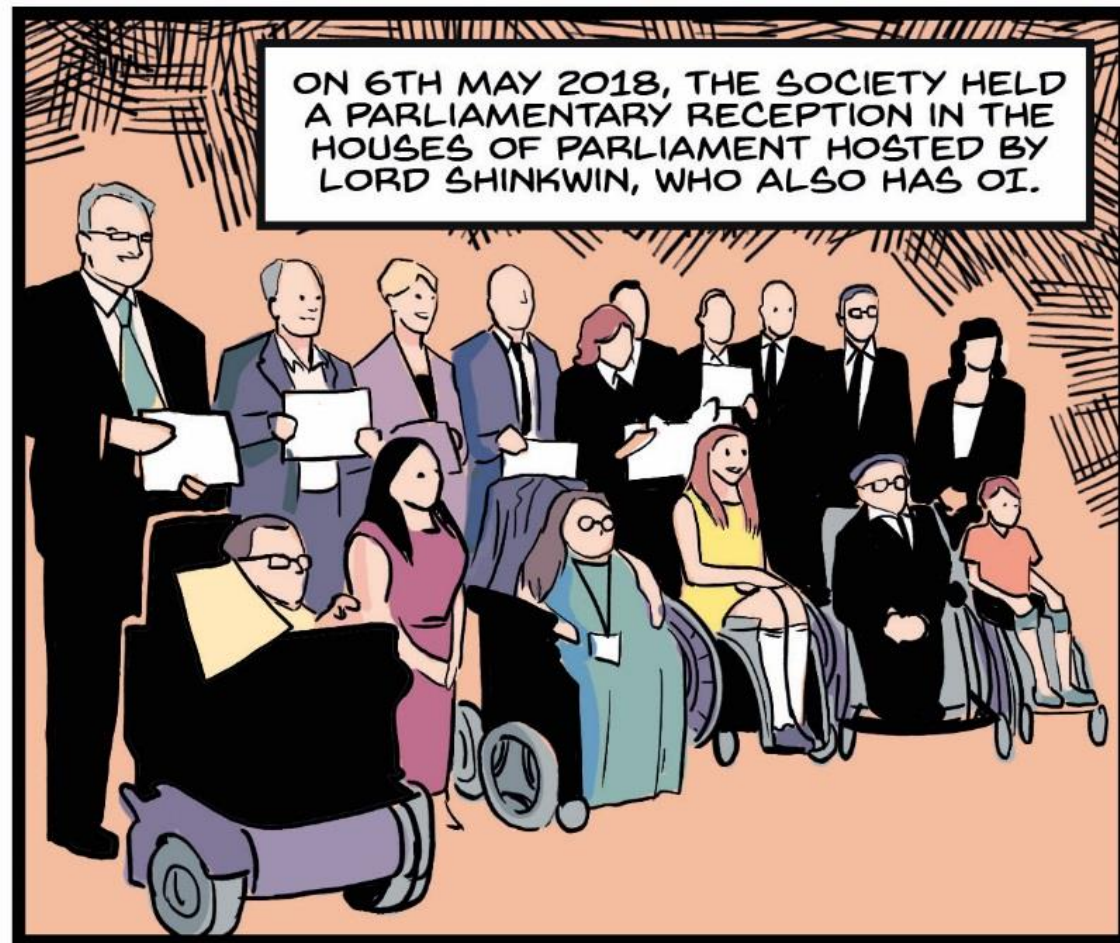
IN 2012, YEARS OF WORK FROM PATRICIA, THE TRUSTEE BOARD, AND CHAIRPERSON ELAINE HEALEY PAID OFF WITH THE APPOINTMENT OF THE MEDICAL ADVISORY BOARD, AND THEN A RESEARCH COMMITTEE IN 2016, WHICH ARE BOTH COMPRISED OF LEADING HEALTHCARE SPECIALISTS IN THE FIELD OF OI.



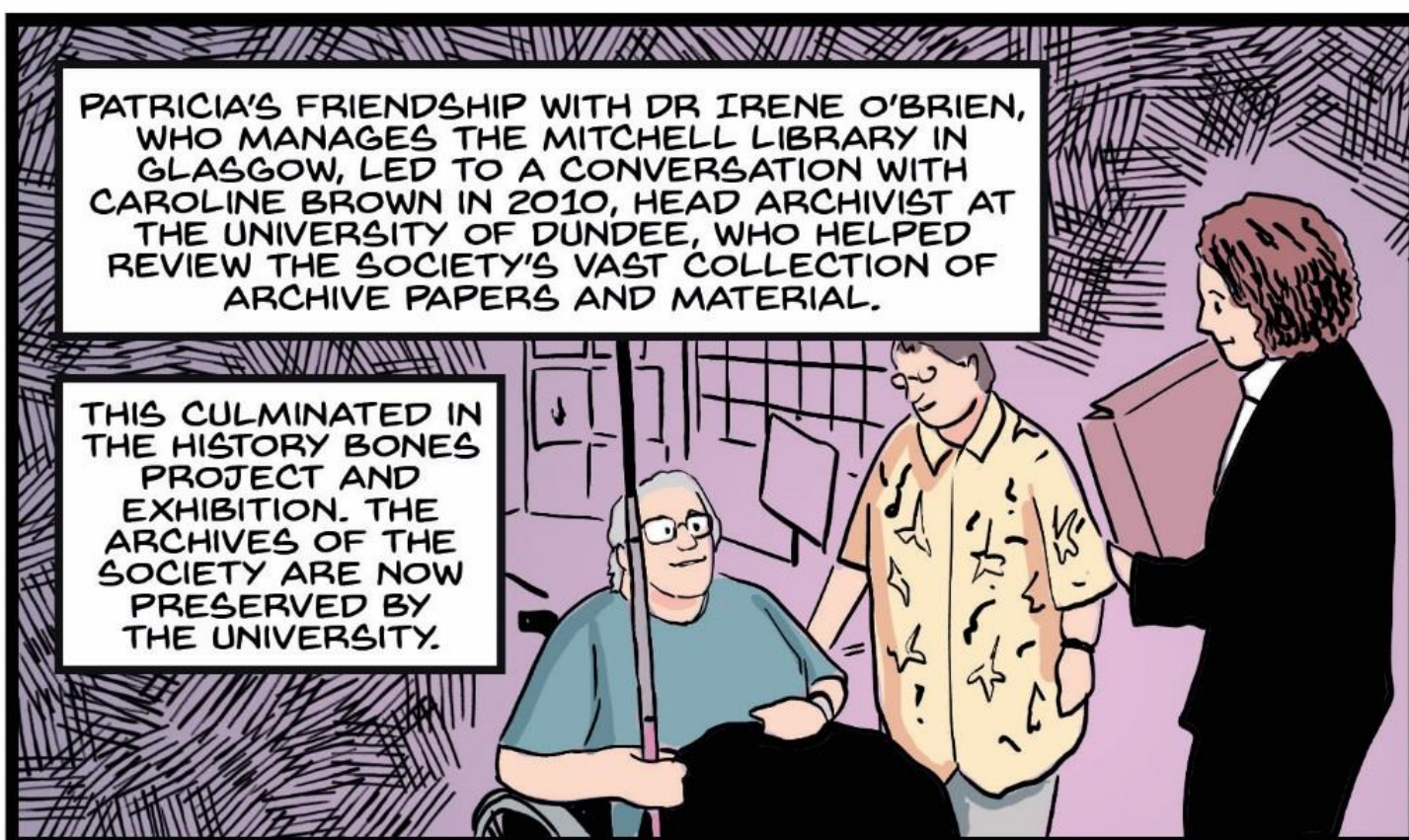
A RESEARCH GRANTS PROGRAMME WAS ESTABLISHED IN MAY 2017. PATRICIA AND ELAINE CONSIDER THESE ACCOMPLISHMENTS TO BE SOME OF THEIR VERY PROUDEST MOMENTS.



IN 2018 THE BRITTLE BONE SOCIETY CELEBRATES ITS 50TH ANNIVERSARY.

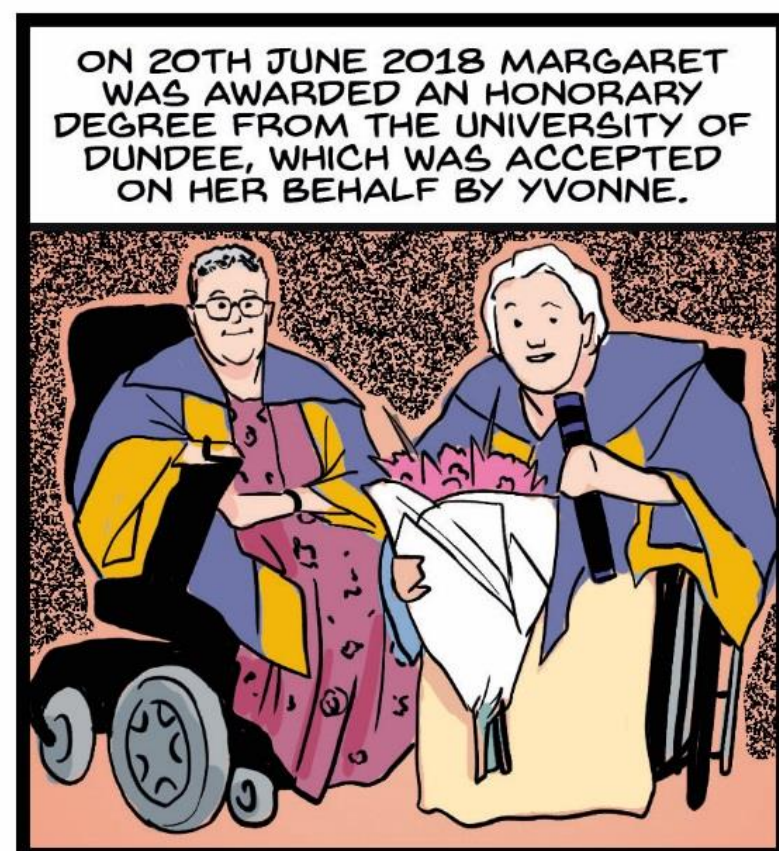


ON 6TH MAY 2018, THE SOCIETY HELD A PARLIAMENTARY RECEPTION IN THE HOUSES OF PARLIAMENT HOSTED BY LORD SHINKWIN, WHO ALSO HAS OI.



PATRICIA'S FRIENDSHIP WITH DR IRENE O'BRIEN, WHO MANAGES THE MITCHELL LIBRARY IN GLASGOW, LED TO A CONVERSATION WITH CAROLINE BROWN IN 2010, HEAD ARCHIVIST AT THE UNIVERSITY OF DUNDEE, WHO HELPED REVIEW THE SOCIETY'S VAST COLLECTION OF ARCHIVE PAPERS AND MATERIAL.

THIS CULMINATED IN THE HISTORY BONES PROJECT AND EXHIBITION. THE ARCHIVES OF THE SOCIETY ARE NOW PRESERVED BY THE UNIVERSITY.



ON 20TH JUNE 2018 MARGARET WAS AWARDED AN HONORARY DEGREE FROM THE UNIVERSITY OF DUNDEE, WHICH WAS ACCEPTED ON HER BEHALF BY YVONNE.



AND THE SOCIETY HAS EVEN WORKED WITH THE UNIVERSITY OF DUNDEE'S DUNDEE COMICS CREATIVE SPACE TO CREATE A COMIC.

DUNDEE COMICS CREATIVE SPACE



HAPPY ANNIVERSARY

OF COURSE,
HUGE THANKS GO
TO ALL THE MEMBERS
OF THE SOCIETY, ALL THE
VOLUNTEERS, AND WE
MUST TAKE A MOMENT TO
RECOGNISE AND APPLAUD
THE HUGE SUPPORT WE
RECEIVE FROM
OUR FUNDERS.

A HEARTFELT
THANK YOU TO
EVERYONE.



Alexander Moncur

Awards for All

Barchester Charitable Foundation

BBC Children in Need

The Elfar Foundation

Equipment for Independent Living

Florence Nightingale in Aid of Sickness

Garfield Weston Foundation

GM Morrison

Gordon Fraser Charitable Trust

Hugh Fraser Foundation

Independence at Home

JTH Charitable Trust

Margarets Fund

Northwood Trust

PF Charitable Trust

RJ Larg Family Trust

Roberston Trust

St James Place Foundation

St Katharines Fund

Stafford Trust

Tay Charitable Trust

The ACT Foundation

The Gannochy Trust

The Hospital Saturday Fund

Variety Club

William Sword Charitable Trust

AND THE LAST WORDS
GO TO MARGARET
HERSELF, IN A POEM
SHE WROTE CALLED
"A SPECIAL GRACE":

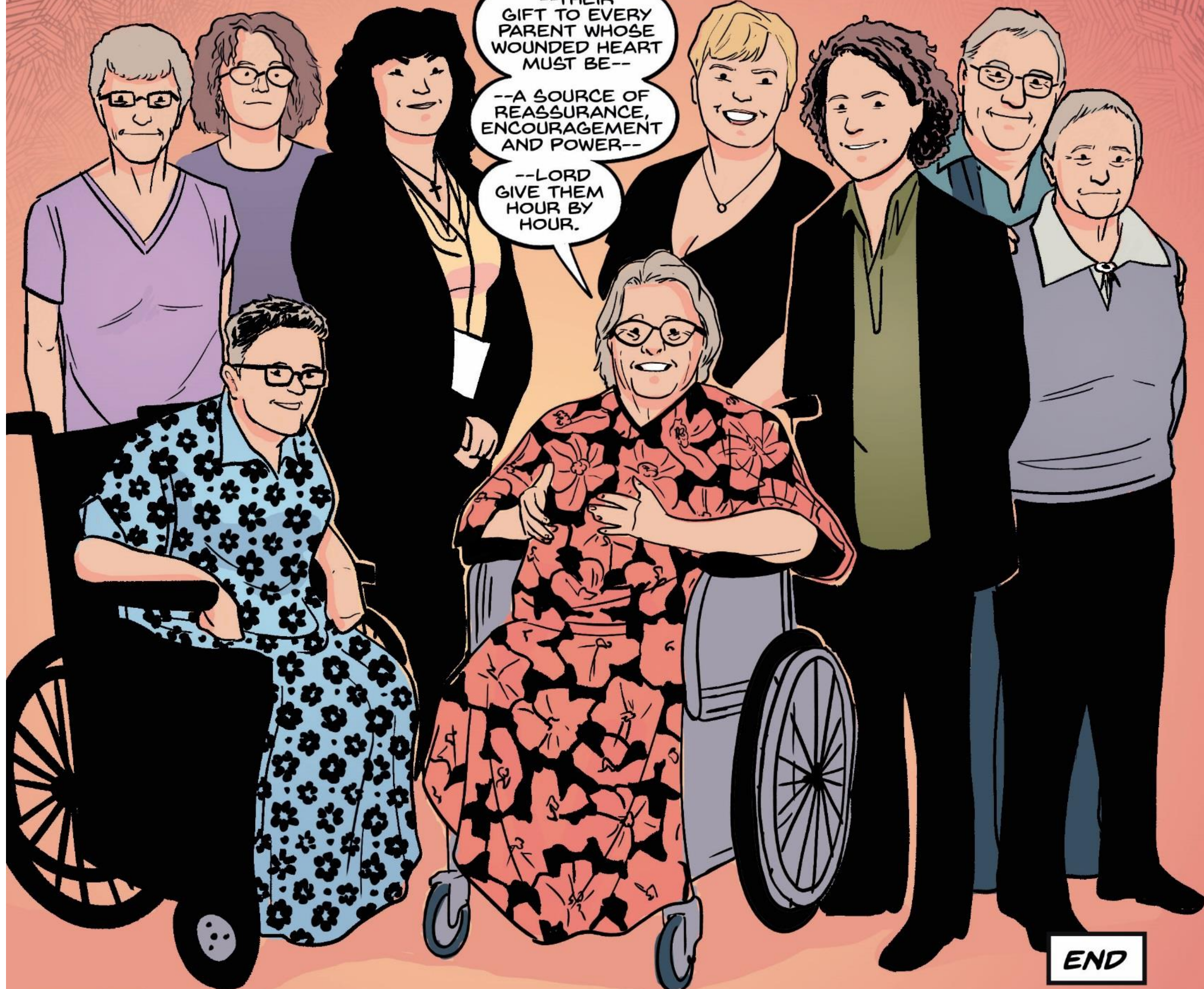
TO THE
PARENTS OF
THE CHILDREN,
WHOSE FEET
DO NOT KEEP
PACE--

--WITH THE
RUNNING OF THEIR
PLAYMATES WHO
DO NOT HEAR
NOR SEE--

--THEIR
GIFT TO EVERY
PARENT WHOSE
WOUNDED HEART
MUST BE--

--A SOURCE OF
REASSURANCE,
ENCOURAGEMENT
AND POWER--

--LORD
GIVE THEM
HOUR BY
HOUR.



END

What is Osteogenesis Imperfecta?

Osteogenesis Imperfecta (OI) is a genetic bone disorder characterised by fragile bones that break easily. It is also known as brittle bone disease. A person is born with this disorder and is affected throughout their lifetime.

OI is a disorder of collagen, a protein which forms the framework for the bone structure. In OI the collagen may be of poor quality, or there just may not be enough to support the mineral structure of the bones. This makes the bones weak and fragile and results in the bones being liable to fracture at any time, even without trauma.

OI is a rare condition and it is estimated that the number of people born with the condition is approximately 1 in every 15,000: that equates to around 5000 individuals in the UK living with OI.

What causes the condition?

OI is caused by a genetic mutation that affects the production of collagen, which can be found throughout the body, especially in a person's bones and other tissues. A genetic condition such as OI can be hereditary and passed on from parents to children. Around 25% of children with

OI are born into a family where there is no family history of the condition. This occurs when the child has a "new" or "spontaneous" dominant mutation.

What are the symptoms?

OI exhibits wide variations in appearance and severity, so a classification system has been identified to describe the different types of OI. Severity can also be described as mild, moderate, or severe. Some people with OI hardly have any symptoms, but in others, OI may lead to physical disability requiring the use of walking sticks, walking frames and wheelchairs.

As the composition of collagen in the bone is not correct, even when there are no fractures there will be other problems connected to the condition; such as the ligaments stretch more easily, joint hypermobility can significantly affect the quality of life as it results in fatigue of many muscle groups. As a result, the mobility and performance of ordinary tasks of everyday living are impaired. Other symptoms can be; hearing loss, fatigue, joint laxity, curved bones, scoliosis, blue sclerae, dentinogenesis imperfecta (brittle teeth), and short stature amongst other medical problems.



For more information see our factsheets and films on our website at:
<http://brittlebone.org/support/information-resources/>

THE MEET UP

THE BRITTLE BONE SOCIETY ANNUAL MEETING.

SORRY, ARE THESE SEATS TAKEN?

NO, GO RIGHT AHEAD. IT'S BEEN A LONG DAY, EH?



YES, BUT SO **USEFUL**. WE'VE LEARNED A LOT. MY NAME IS SOPHIE AND THIS IS MY PARTNER, BRIAN.

HELLO. I'M DAVID, AND THESE ARE MY FRIENDS AUDREY AND DAPHNE.

THIS IS OUR FIRST TIME. WE HAVE A LITTLE GIRL WITH OI.

AWW. BLESS. HOW OLD IS SHE?

SHE'S JUST ONE YEAR OLD. SHE'S WITH GRANNY AT THE MOMENT.

DID YOU KNOW SHE HAD BRITTLE BONES FROM THE START?

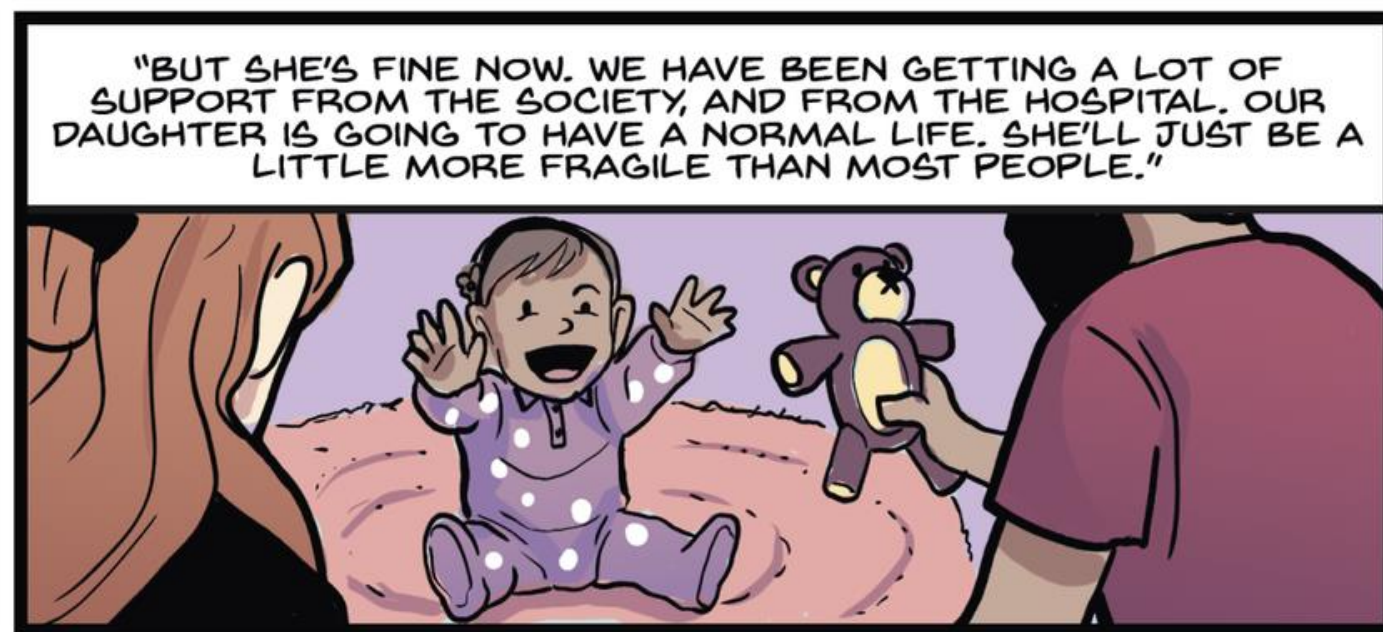
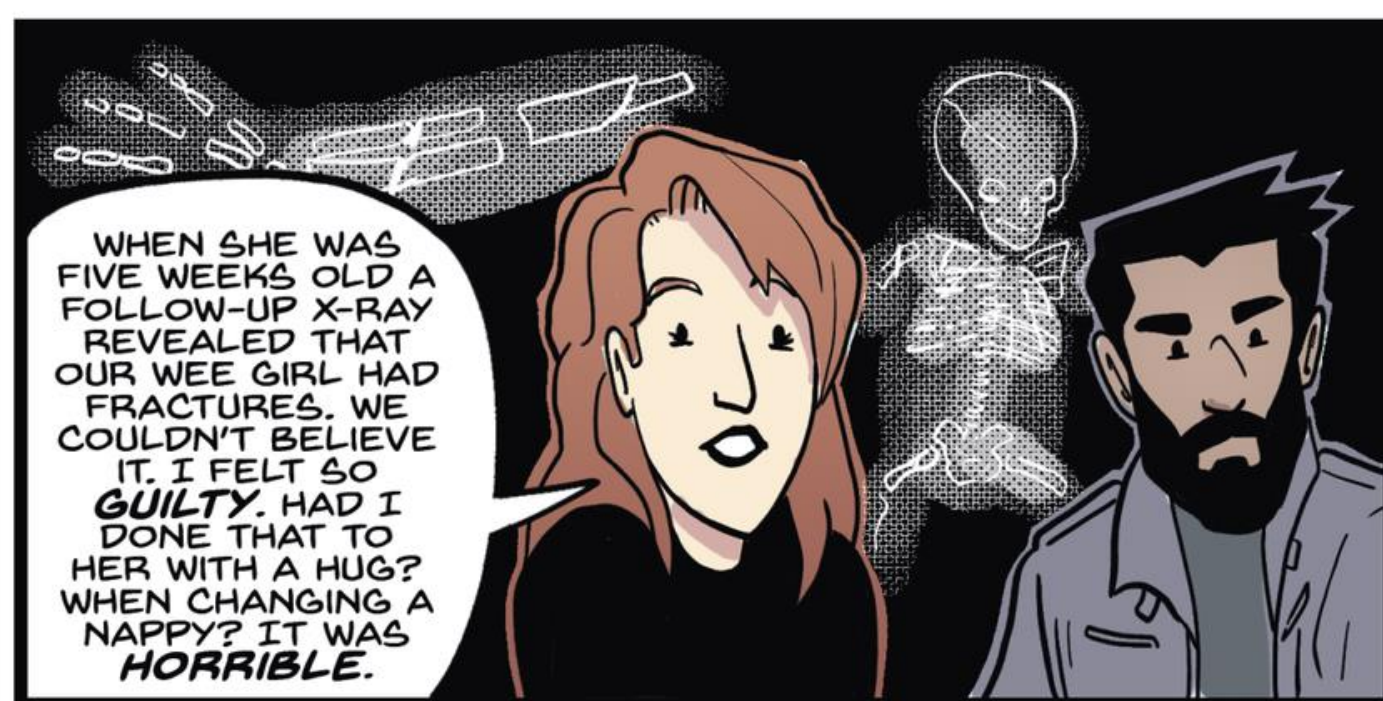
AT OUR 20-WEEK SCAN, WE WERE TOLD SHE WASN'T MEASURING PROPERLY.



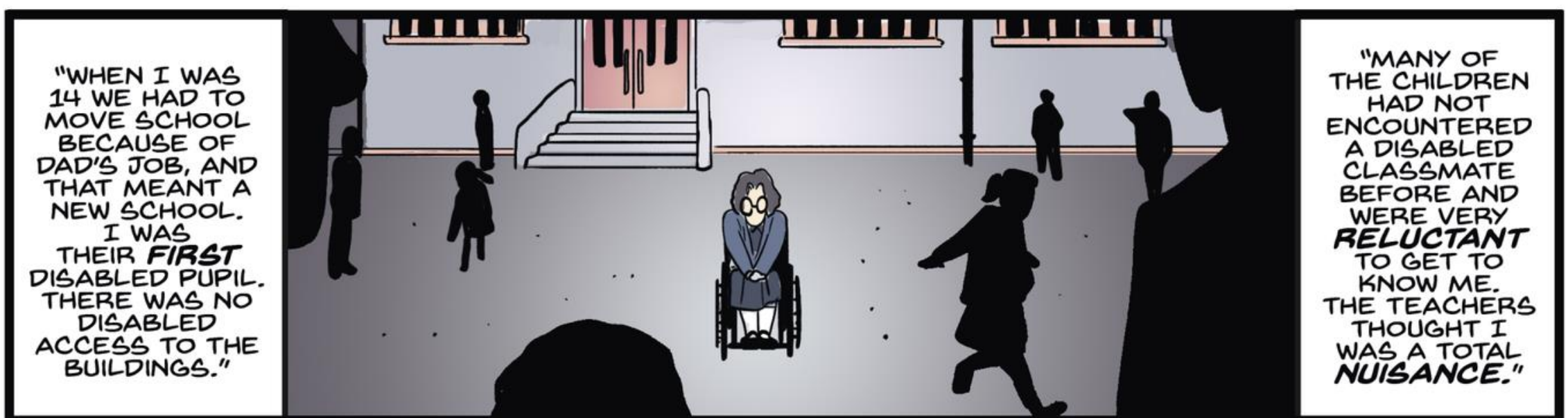
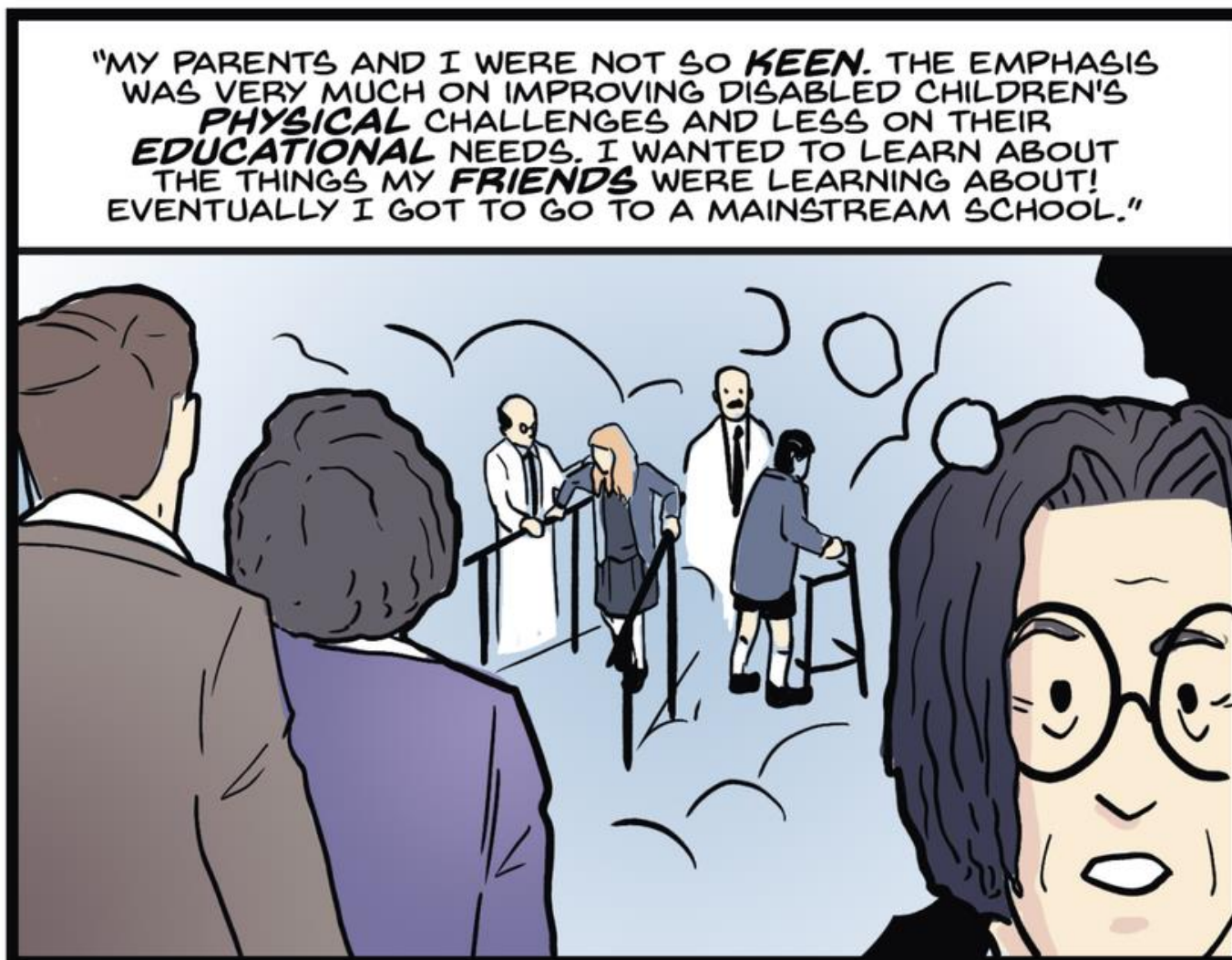
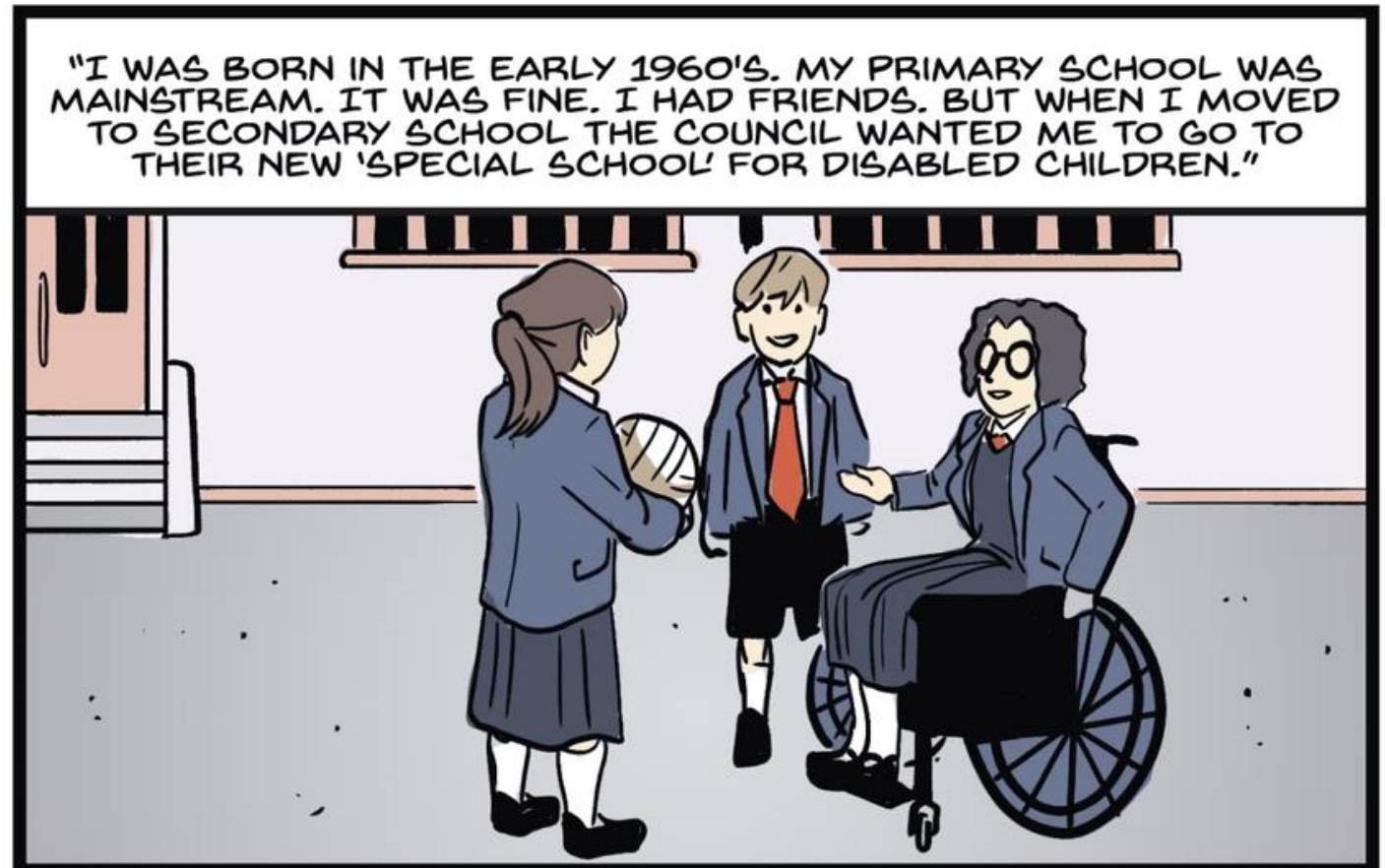
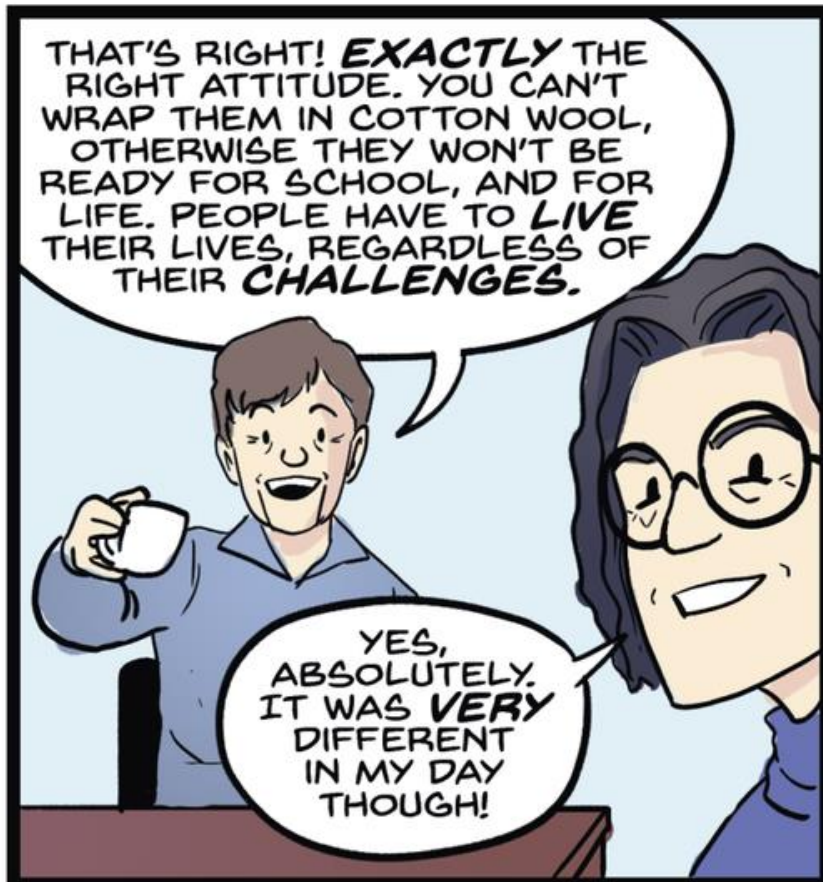
"IT WAS PRETTY SCARY. WE WERE TOLD TO EXPECT DWARFISM. THEN THEY SAID THAT OUR BABY WOULD BE LUCK TO SURVIVE PAST **36 WEEKS**. THEY OFFERED A TERMINATION, BUT WE TRIED TO STAY POSITIVE."

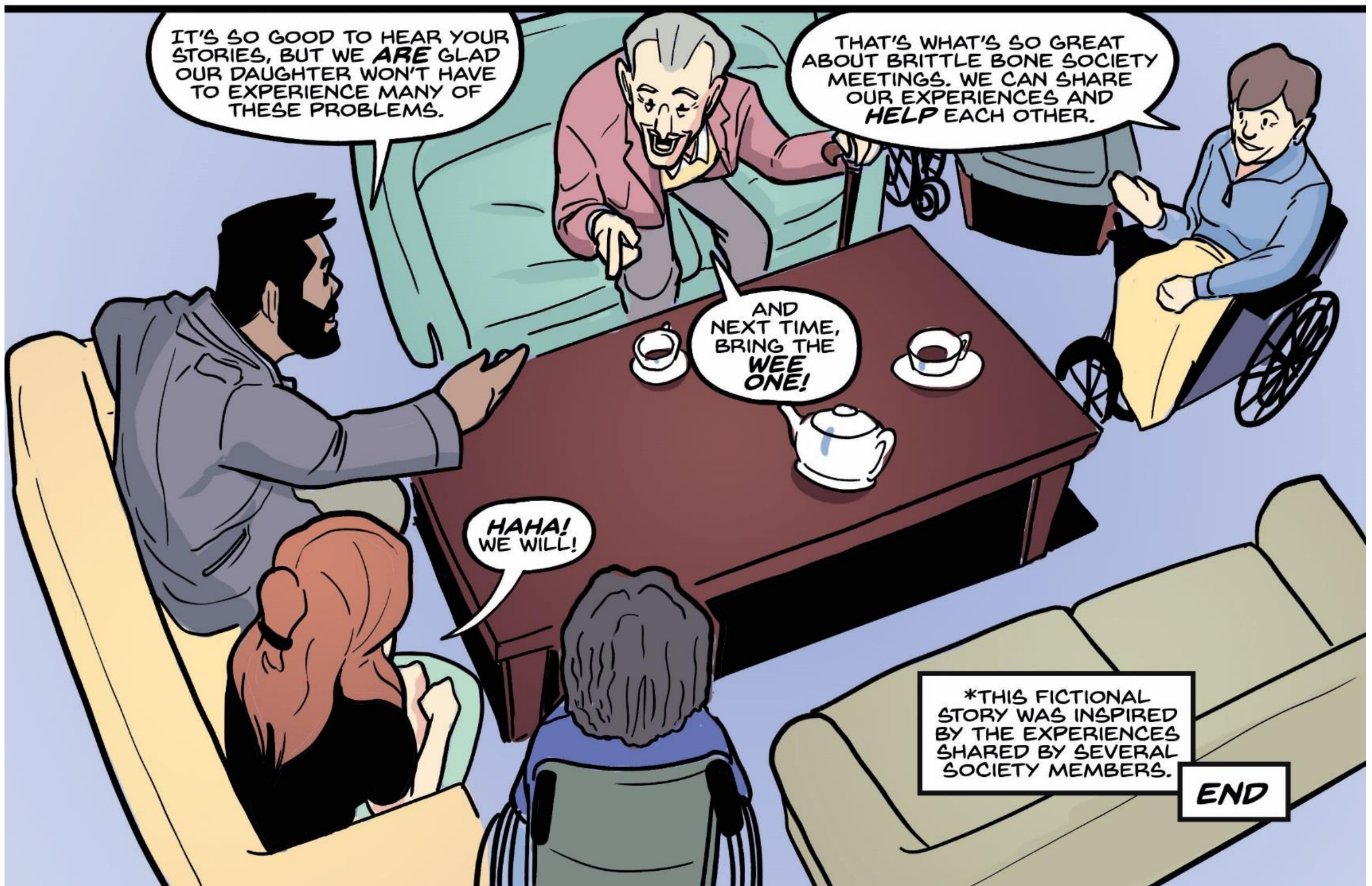
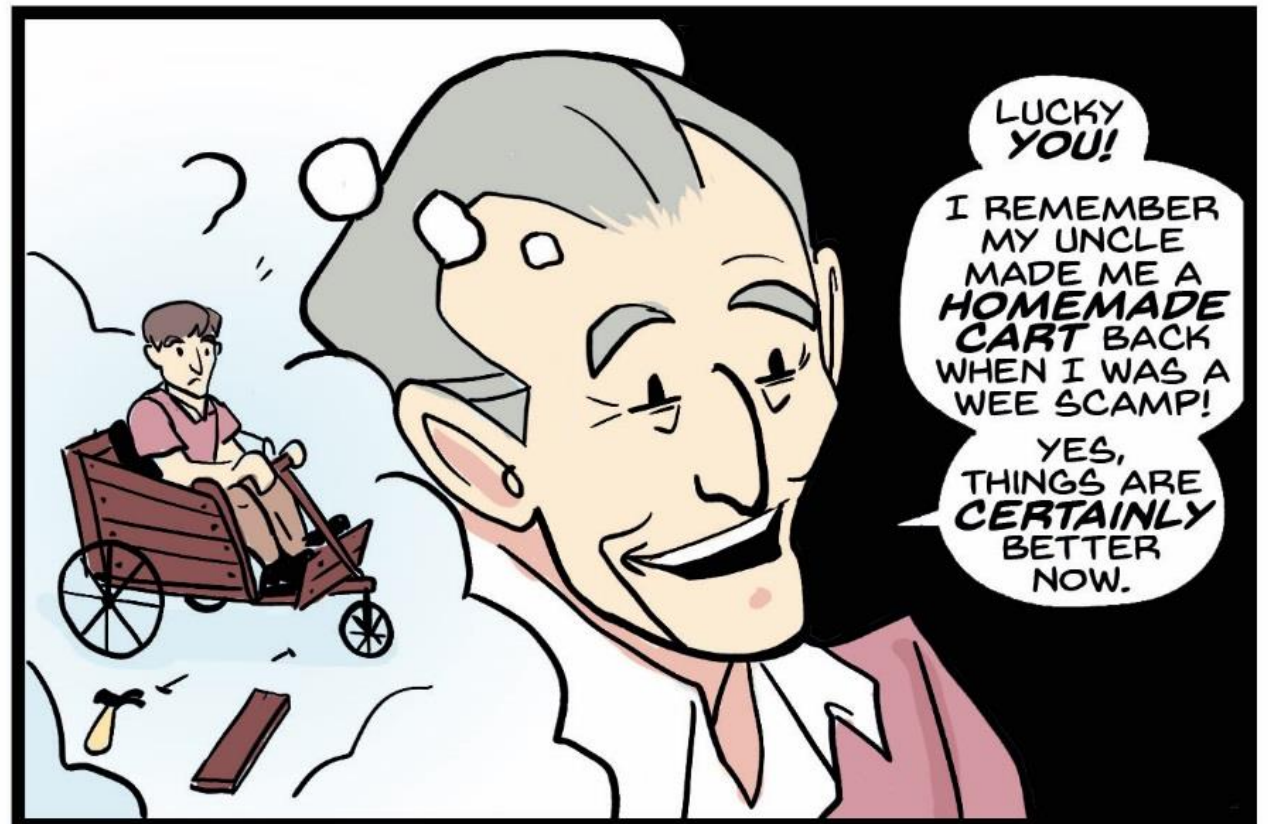
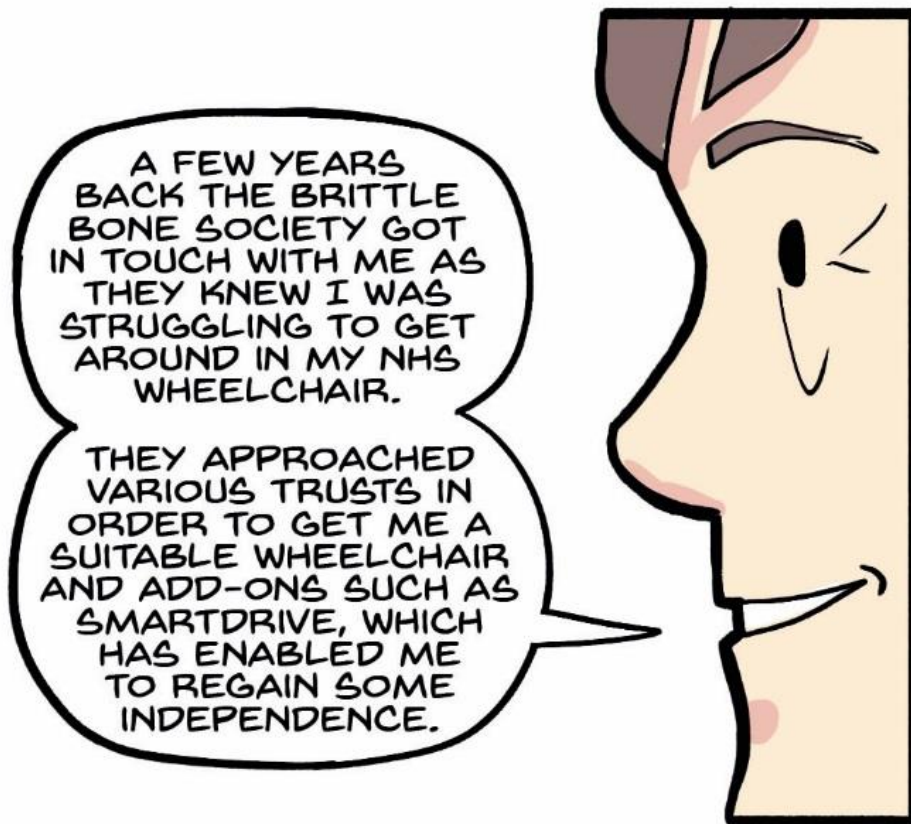
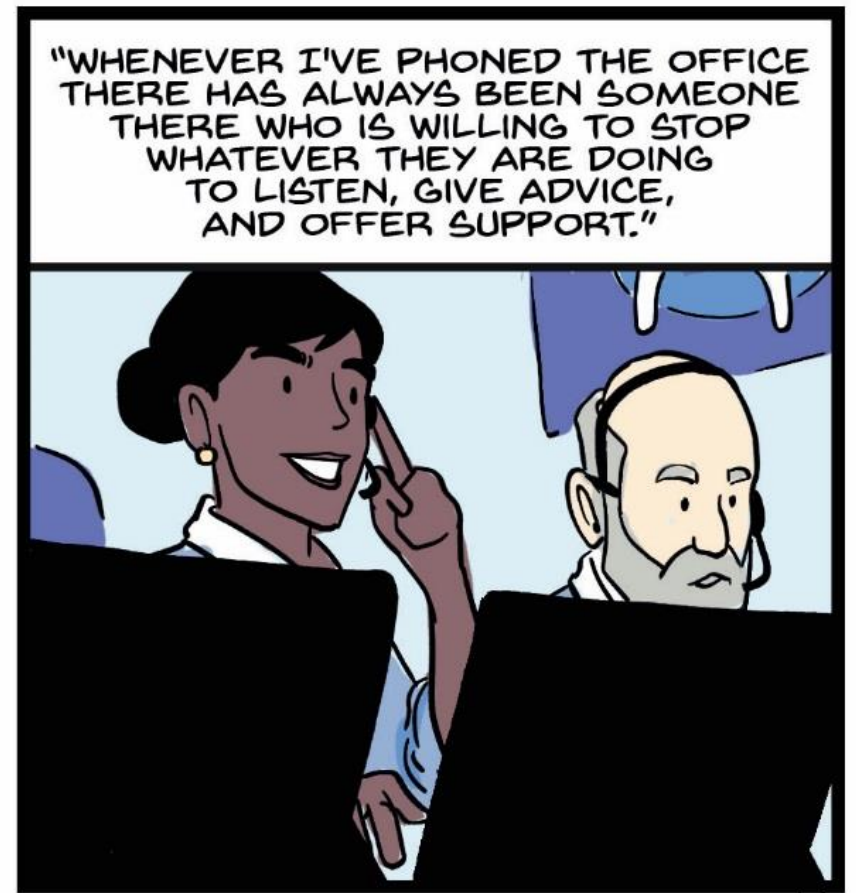
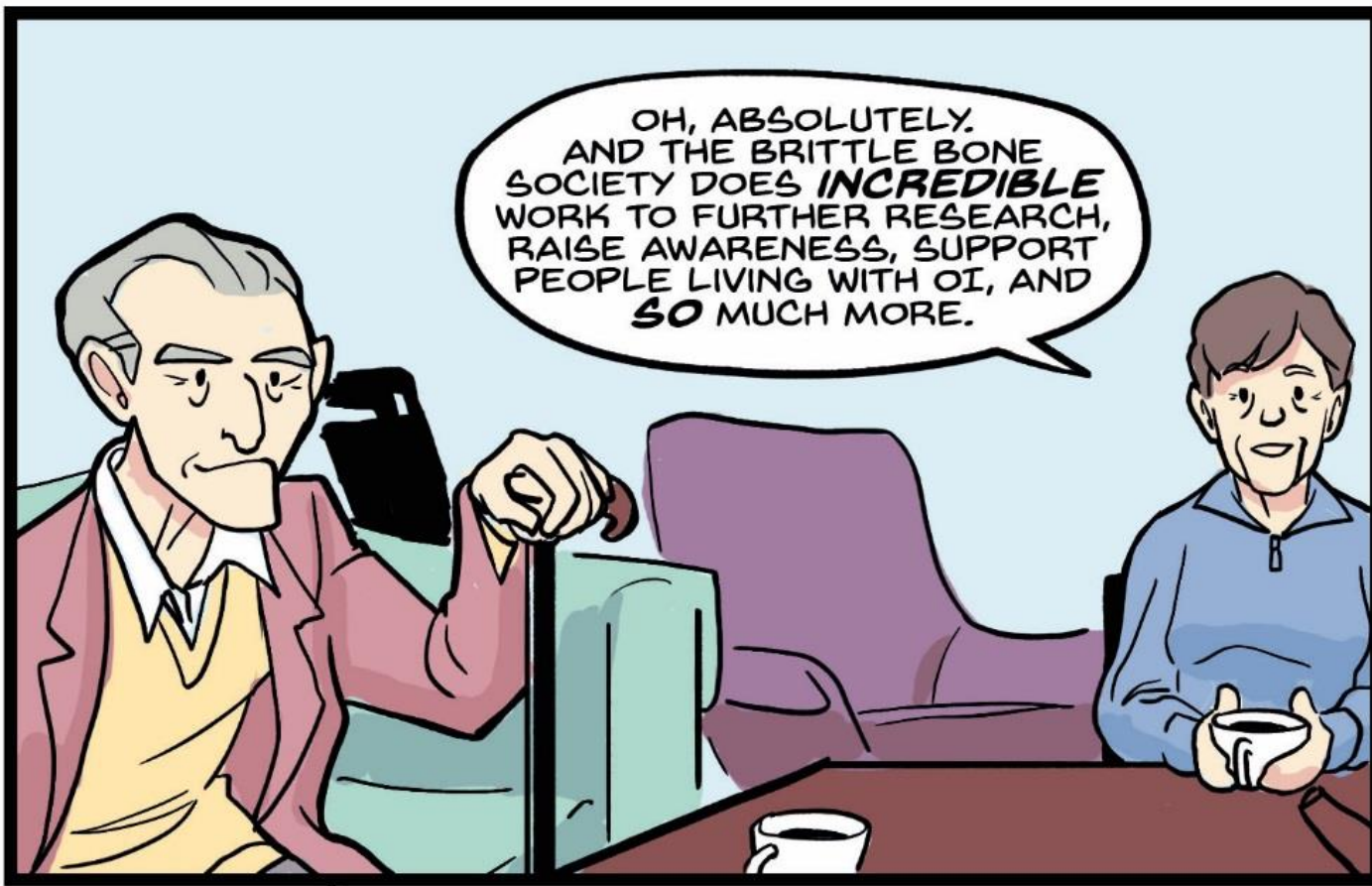
WHEN SHE WAS FIVE WEEKS OLD A FOLLOW-UP X-RAY REVEALED THAT OUR WEE GIRL HAD FRACTURES. WE COULDN'T BELIEVE IT. I FELT SO **GUILTY**. HAD I DONE THAT TO HER WITH A HUG? WHEN CHANGING A NAPPY? IT WAS **HORRIBLE**.

"BUT SHE'S FINE NOW. WE HAVE BEEN GETTING A LOT OF SUPPORT FROM THE SOCIETY, AND FROM THE HOSPITAL. OUR DAUGHTER IS GOING TO HAVE A NORMAL LIFE. SHE'LL JUST BE A LITTLE MORE FRAGILE THAN MOST PEOPLE."



"THEN OUR BEAUTIFUL GIRL ARRIVED, SHE WAS PERFECT. WE WENT HOME AND EVERYTHING SEEMED FINE."

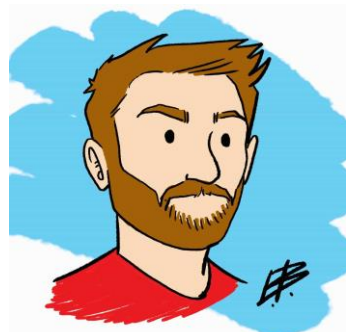




Contributor Biographies



Professor Chris Murray is Chair of Comics Studies at the School of Humanities, University of Dundee. He is Associate Dean for Knowledge Exchange and Partnerships, leads the MLitt in Comics and Graphic Novels course, and is Director of the Scottish Centre for Comics Studies and Dundee Comics Creative Space. He has published on the British Superhero, Alan Moore and Grant Morrison, horror comics, comics and literature, and comics and propaganda. He is co-editor of *Studies in Comics* (Intellect) and *Universe Comics*, and Co-organiser of the International Comics And Graphic Novels Conference. He has written and produced several public information comics for research and engagement purposes.



Elliot Balson is a Dundee-based comic artist. His work can be found in various UniVerse publications, *Comichaus*, and an upcoming anthology called *Masks*. He is currently working on his own series, *Untethered*, with writer Umar Ditta.



Catriona Laird is a Scottish illustrator and comic artist based in Ink Pot Studio in Dundee. She was winner of the SICBA award for Up and Coming Talent 2017 and nominated for Best Artist, Best Writer and Best Single issue for her comic *Stinger*. In 2018 Catriona was nominated for best artist for her ongoing webcomic *Chimerical*. Catriona is currently working on the upcoming graphic novel *Nasty Girls* with writer Erin Keepers and publisher George Lennox.



Dr. Damon Herd is the Coordinator of the Dundee Comics Creative Space. He is also an artist and researcher with a PhD in Comics from the University of Dundee. His research area is autobiographical comics, performance, and the games authors play with truth. He is the founder of DeeCAP (Dundee Comics/Art/Performance).



Dr. Golnar Nabizadeh joined the University of Dundee as Lecturer in Comics Studies in September 2016. Her research focuses on comics and visual studies and particularly on representations of trauma, migration, and memory in these fields. Golnar received her PhD in English and Cultural Studies from The University of Western Australia, and has a monograph forthcoming with Routledge entitled *Representation and Memory in Graphic Novels*.



Phillip Vaughan is a Senior Lecturer and the Course Director for the MSc in Animation & VFX and the MDes in Comics & Graphic Novels programmes at the University of Dundee. He is also the creator and coordinator of the Level 3 Comic Art & Graphic Novels module at Duncan of Jordanstone College of Art & Design. In 2015 he became the Art Director of the Dundee Comics Creative Space. He is Co-Investigator on the ESRC funded project: *Comic conventions: Words and Pictures: Understanding how people gather information conveyed jointly through text and image in comics*. He also co-edits and produces UniVerse Publications titles such as *Anthology* and *The Masters of UniVerse*, which publishes work by comics students and is the Art Director of the Scottish Centre for Comics Studies and also *DiamondSteel Comics Saltire* series.

With thanks to Patricia Osborne, Coreen Kelday and the Brittle Bone Society.

